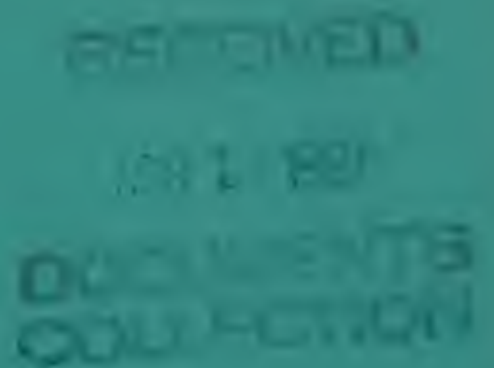
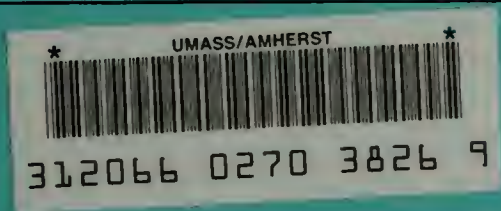


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Governor's Commission on Mental Retardation

INNOVATIONS IN
INDIVIDUALIZED HOUSING
FOR PEOPLE WITH
MENTAL RETARDATION

*Report from the Commission's Public Hearing held
Tuesday, May 9, 1995 at Worcester State College*

INNOVATIONS IN INDIVIDUALIZED HOUSING FOR PEOPLE WITH MENTAL RETARDATION

The Commonwealth of Massachusetts

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I. INTRODUCTION

"Life, liberty, and the pursuit of a home of your own."

--Tom Riley, Executive Director, Better Community Living

Finding affordable, quality housing is a struggle for many Americans. For many citizens with mental retardation and other developmental disabilities, finding a place to call home can be an almost impossible task. These individuals too often lack the financial resources, support, or community connections to make decent affordable housing a reality. In addition, the human service system's response to this situation is to offer housing that is fundamentally different from the traditional concept of home. Many individuals with mental retardation are placed into residences that are owned and controlled by other people. Those placed in group facilities may face bans on fireplaces, fences that hinder contact and weekends filled with shift staff. Such situations bear little resemblance to the general understanding and concept of home. "Home is where we can be with the people with whom we want to be; it is a haven from those with whom we don't want to be. Home is the foundation of our personal liberty and our pursuit of happiness. It is the center of our community participation and our independence in daily living" (O'Brien, 1994).

The environment is starting to change--at the national and state levels, among the local human service agencies, in the banking industry and in the advocacy community. Significant efforts are underway to modify the human service perspective and direction in developing housing and supports for people with mental retardation. The field of human service professionals is focusing on moving support to where people live. Instead of concentrating on how to make the individual adapt to the environment, ways of adapting the environment and supports to the individual are being explored. A key element in the emerging paradigm of support is a commitment to the community as the place where people should live. The job of the practitioner in this framework is to help remove the barriers that keep the individual from participating in his or her chosen community.

The President's Committee on Mental Retardation issued a major report in 1994 which featured significant observations and recommendations about consumer-controlled housing. The report, *The National Reform Agenda and Citizens with Mental Retardation: Putting People First*, stated that changes in federal policy will be "crucial" to developing consumer-controlled housing. The Committee noted that the "government has considerable leverage through its housing program, income support policies, and public relations efforts. Through modifications in these programs, the federal government can plan an affirmative leading role in housing reform for people with mental retardation."

In Massachusetts, the Department of Mental Retardation funds residential services for approximately 9,300 people with mental retardation through provider-operated and state-operated programs, including community programs and facilities. In fiscal year 1996, residential supports cost approximately \$500 million, or 68% of the DMR budget. In FY'95 there were 9,300 individuals living in residential programs. Of these 9,300 individuals, 4,300 lived in residences for more than four people, including the approximately 1,950 people living in state institutions. Very few individuals own their own homes.

The Massachusetts Governor's Commission on Mental Retardation recognizes and supports the development of stable, affordable housing for adults with mental retardation and other disabilities. Under Executive Order 356, the Governor's Commission on Mental Retardation is mandated to conduct at least two public hearings annually, the purpose of which is to highlight, among other issues, the extent to which the mental retardation services system provides opportunities for persons with mental retardation. Accordingly, in May, 1995, the Governor's Commission convened a public hearing to solicit innovative housing options and technologies and to review strategies for providing individualized supports for those in need.

The hearing brought together 85 individuals, including experts in housing development, banking, real estate, human service policy development, advocates, parents, and service providers. Participants were keenly aware that what is needed is a new way of thinking about how individuals with disabilities can have choices about where they live, with whom they live, and how needed supports are provided. In oral and written testimony, the stakeholders echoed the need for a common person-centered planning process, development of innovative home purchasing opportunities, individual budgets, and support strategies that respect the needs and preferences of each consumer. The hearing focused on barriers to financing individualized housing for persons with disabling conditions, potential resources and solutions to the dilemma, and provided concrete recommendations for implementation.

It is difficult to consider housing reform in isolation from the other needs of people. Most people with developmental disabilities need access to long-term services and supports and, without them, few can aspire to own homes of their own. Supports can be provided by individuals employed by disability services,

community or employment agencies, people employed by the individual with a disability, people acting on the person's behalf, or a person freely offering support and services without reimbursement. The key is to allow a variety of different options.

People providing supports have a variety of relationships with a person with a disability--neighbor, relative, friend, family member, co-worker, roommate, acquaintance, or other community member. The choice of the provider of these supports should generally be left to the discretion of the person with a disability. In order to facilitate an "acceptable and supportive" living arrangement, agencies and people should be prepared to assist for as long as necessary and to adjust the levels and types of supports to reflect the person's life circumstances.

Acknowledging the need for flexibility and variety in housing options for the disabled, this report describes and highlights information on innovative housing approaches and details emerging issues in four major sections:

- A historical context for housing development including key testimony from Robert Laux,
- A national overview of innovative financing and program development options,
- A summary of the major themes expressed at the hearing,
- A list of specific recommendations for policy reform within the mental retardation service system.

II. SCOPE OF THE PROBLEM

Since the 1970s, the United States has witnessed a noticeable decline in home ownership, affordable and available rental units, and an increase in the number of people who are homeless. Schwartz, Ferlauto, and Hoffman (1988) list the four demographic factors that will pose the greatest challenge to housing policy in the 1990s:

- the increase in the number of people 75 and older;
- the sharp upturn in the number of single people living alone and in single-parent, female-headed households;
- the increase in young families buying homes; and
- the large concentration of poor families, which is expected to increase by almost 6 million in the 1990s.

The wealthy have few housing problems; people with mental retardation, however, are overwhelmingly poor. Like other poor people in the United States, they have great difficulty in finding safe, affordable housing. The limited number of affordable units across the country is often a far greater obstacle to independence and self-sufficiency than the clinical nature of a person's disability. The difficulties people with mental retardation encounter in securing homes of their own have been even further exacerbated by a history of devaluation, discrimination and segregation.

It is difficult to focus on housing issues without also considering the array of supports needed to attain the goal of inclusive community life. A comprehensive review of research related to housing and community integration for all disability groups (Carling, Randolph, Blanch, and Ridgway, 1988) concluded that "supports are the critical factor that determine if a person can stay in housing of his or her choice, and lack of supports can lead to transience, dislocation, and the risk of reinstitutionalization." Greater attention is being paid today to the typical ways in which we all obtain support. The human service system is exploring how people with disabilities can become full members of the community, whether this happens through the assistance of friends, family, co-workers, roommates, or organizations. A housing and support approach must be based on the philosophy that whatever supports are wanted and needed should be available, and supports should be individualized and flexible. Therefore, supports should be able to be changed or altered without the person having to move.

TYPES OF SUPPORT

- | | |
|-----------------------------------|---|
| ✓ live-in roommate | ✓ meals on wheels |
| ✓ homemaking and related tasks | ✓ emergency back-up systems |
| ✓ support from a neighbor | ✓ health care |
| ✓ personal assistance | ✓ work-related assistance |
| ✓ peer support | ✓ appliances, home furnishings, and other goods |
| ✓ basic academic skills | ✓ housing-related assistance |
| ✓ facilitation of decision-making | ✓ income subsidy |
| ✓ coordination | ✓ community connection, relationships and social interactions |
| ✓ adaptive equipment | |

(Racino, Walker, O'Connor, Taylor, 1993)

There are no simple solutions when attempting to resolve who needs "around the clock" support and who does not. However, whether a person will require 24-hour supervision will depend not only on the skills and characteristics of the person, but also on what other supports are available besides on-site staff. A most critical issue to consider is how support can be provided in individualized and flexible ways. Today, some agencies are beginning to stress interdependence, which assumes that everyone needs some type of support in his or her daily life. For some people, this support will need to be long-term and ongoing, but it should not preclude their living in a home of their own. There are an infinite number of strategies that can be used to support people in homes in the community; service systems must remain diligent in adapting new methods and procedures to accommodate persons with mental retardation.

It should be noted, however, that for some individuals with severe disabilities the issue of providing adequate and appropriate supports is paramount regardless of where the individuals might live. The provision of services and supports should be dictated by the individual's needs and circumstances, not by the living environment. Several disability organizations and agencies are beginning to encourage approaches that are less bureaucratic and provide greater opportunities for spontaneity to occur in the lives of people with severe disabilities. Agencies are now looking at ways to start with the person first, and support staff are developing new skills to get to know people better and to assist in the creation of support options. The focus of a housing

and support approach includes constant attention to quality of life issues from the person's own perspective. Less emphasis is being placed on ways to "fix" people with disabilities and more emphasis is being placed on ways to support their participation and lifestyle.

III. TESTIMONY OF ROBERT J. LAUX, PRESIDENT, WILD RIVER REALTY, BETHEL, MAINE

Drawing on his experience as President of Creative Management Associates and Wild River Realty, Robert Laux outlined several issues which continue to hamper the development of individualized housing.

First and foremost is the **failure to utilize the resources available** through the community's existing housing network. Realtors, bankers, appraisers, developers, builders, and city planners are among those working to meet local housing demands. They are the community members who are most knowledgeable about housing resources. However, with efforts directed at the development and operation of segregated residential services, human service administrators often never connect with these individuals. As Mr. Laux emphasized, *"housing is a community issue, not a disability issue. The more we seek to create alternatives which are exclusively used just for people with disabilities, the more we will neglect the other options which exist within each community."*

It is essential for human service administrators to familiarize themselves with the vast array of housing resources available and to *"learn how to manipulate them."* Mr. Laux cited several examples in which housing resources were used creatively to make housing affordable for people on limited incomes. *"We've used community development block grant funds to assist people in buying their own homes through non-profit organizations. We've assisted families in using trust income and assets set up to benefit their son and daughter, and we've used tax credits and bought scattered sites and turned them into affordable housing."* Participants were encouraged to learn the manipulation of the three critical factors which lead to affordable housing options: the cost of property, the cost of money in terms of interest rates, and the use of subsidies.

Figure 1

FISCAL VARIABLES RELATED TO HOUSING

COST OF PROPERTY

Pre-construction Acquisition
Multiple Listings (Realtors)
Distress Sales
Bank Foreclosures
VA/FHA Foreclosures
State Property Developed
Creative Purchase and Sales
Agreements

COST OF MONEY

State Housing Finance
Federal Programs
State DMH/MR
Bonding
Community Trusts
Municipalities
Life Insurance Co.
Foundations
Social Investors
Social Organizations
Community Loan Funds
Family Trusts
Non-Profit Organizations
Community Reinvestment
Banks

SUBSIDIES

State DMH/MR
Federal Section 8
Federal FMHA
Municipalities
SSI/State
Families
Trust Income
Rental Income
County

There is no one way to provide affordable housing; what works is the creative involvement of a wide variety of people with a wide variety of resources. In addition, human service professionals need to mix and match the type of funding subsidies with available monies in order to acquire affordable property (see Figure 1).

Mr. Laux also emphasized that **essential support networks are critical to successful housing situations**. *"Unfortunately, the human service system's response is very often more complicated than it needs to be. We need to assist people in finding and developing friendships, meaningful relationships with people in the community."* The system needs to be creative and flexible, based on an understanding of how communities function and how people associate with each other. Flexible supports that can change over time as a person's needs change are critical. These can include changes in the type of staffing, the number of hours of staff support, or the specific people who provide support. In all of these instances agencies must: *"1) commit to supporting people, not the specific place; 2) be*

willing to invest the time and resources necessary for these changes; and 3) view their role as adapting to whatever changes the person was making in his or her life instead of making life decisions [being] based on program needs."

In closing, Mr Laux highlighted the **critical role that families play in the development of housing** for individuals with disabilities. *"Families can provide resources for the long term. Families can set up trusts that will assist with housing needs in the future. It is not necessary to always rely on the state or the federal government for support, and there is no guarantee that federal or state rules will provide the optimum benefit for your son or daughter."* The best advice for families is to *"start planning early."* There are a variety of financing schemes and scenarios, and families need to *"explore, research, educate themselves and learn to manipulate the system."*

IV. A NATIONAL OVERVIEW OF INNOVATIVE HOUSING OPTIONS

Several states have made a concerted effort to address the needs of their citizens with disabilities, demonstrating the creative use of resources.

In New Jersey, state voters approved a \$160 million bond issue aimed at reducing the waiting list for community services for people with developmental disabilities. Their master plan, *Vision 2000: Community Choices and Challenges*, outlines "new approaches to individualized home ownership and housing opportunities, shared equity and equity for services, grants to create loans for individuals and families to purchase housing." For example, people with disabilities will be able to access very low-cost (1-4%) mortgage money through the New Jersey Housing and Mortgage Finance Authority, due to expanded underwriting criteria that include permitting family members to assist in making a down payment. Individuals who choose this option must have a stable income for at least two years and demonstrate that they have saved at least \$500 of their own funds.

The plan also outlines strategies that enable parents/family members to obtain "reverse mortgages" (e.g., use the equity in their homes) to pay for services and housing on behalf of an individual with disabilities. This program allows the

Reverse Mortgage

Reverse mortgages can help individuals get the income they need to remain in their home and cover their living expenses. Unlike a typical mortgage, where the borrower makes monthly payments until the debt is paid off, a "reverse mortgage" provides income to the borrower, usually in regular monthly amounts. Borrowers do not pay back the loan until the end of the term, when usually the home is sold to satisfy the debt. Because the loan amount is based on the value of the borrower's home, the borrower's ability to repay based on current income is not an issue. Some reverse mortgages are "lifetime" loans, guaranteeing the home will not be sold as long as the owner is living there.

consumer and the family the option to remain together in their principal residence and receive the necessary support services for as long as possible. The program also contains a component that offers the service provider the opportunity to convert the family home (if suitable) to a community living residence for the consumer when the home is no longer occupied by the family. In addition, 5% of the \$6.5 million of the

bond proceeds are being set aside to be "used for competitive grants and seed money to finance housing and support models which incorporate client and family financial participation, including transition/aging out populations, that are not dependent upon state operating funds." These dollars will be used to foster such approaches as housing cooperatives and collectives, limited partnerships, pooled equity arrangements, trusts, and home-sharing programs that are geared to melding private and public resources in support of people with disabilities.

The **Pennsylvania** Office of Mental Retardation, in cooperation with the state's Housing Finance Agency and the Self-Determination Housing Project, have launched demonstration projects that will develop a variety of approaches to providing home ownership or lease control to people with developmental disabilities. These projects are bringing together consumers, lenders, housing developers, architects, service providers, government officials, and others to promote housing that is affordable, accessible and integrated.

The projects are being supported by funding through the Office of Mental Retardation, the Developmental Disabilities Planning Council, Fannie Mae (the Federal National Mortgage Association), the Philadelphia Office of Community Development and the Allegheny County Department of Development. Financial support will range from grants for program planning and administration to down payment and closing-cost assistance for first mortgages. The state housing finance agency will provide up to \$2,500 per home buyer for home ownership counseling and closing costs in addition to first mortgages.

The Pennsylvania Project is providing information to make lenders aware of a market they may have previously overlooked, and to facilitate the process of home ownership for persons with disabilities.

What Lenders Can Do to Help Persons with Disabilities Become Home Owners:

- ✓ **Ask lenders to meet applicants at locations other than banks.** Transportation can be a problem for people with disabilities.
- ✓ **Ask lenders to modify their customary debt-to-income ratio.** Persons with disabilities often don't have the same high level of debt and expenses as other applicants, so even though they have less income, it may be sufficient to manage a mortgage and other monthly costs.
- ✓ **Ask for discounts on loan rates, points or closing costs.** Persons who successfully complete a pre-loan home buyer or home ownership counseling program, or who agree to participate in an ongoing counseling program, can receive reduced rate loans.
- ✓ **Ask for accommodations for persons who require structural modifications in their homes.** Lenders can include the cost of physical modifications to make a home accessible in the loan amount.
- ✓ **Assist applicants with asset restrictions.** Persons receiving Supplemental Security Income (SSI) are restricted from accumulating more than \$2,000 in savings. Ask lenders to set up an escrow account into which applicants make periodic deposits in order to accumulate sufficient funds for down payments.
- ✓ **Considerations for joint mortgage applications from unrelated adults.** By pooling resources and income, persons on SSI who normally could not afford a home on their own can manage the expenses together.

(Community Services Reporter, Volume 3, 1996)

New York's Office of Mental Retardation and Developmental Disabilities (OMRDD) believed in the concept of "home sharing" and provided funds to encourage families and providers to integrate this option into the residential service network. Funds were awarded to spearhead a joint effort between the OMRDD and the state Office for Aging. As of September 1994, 91 individuals were in home sharing settings across the state. Of the 91 participants, 71% have mental retardation. One of the most enlightening findings identified was the use of subsidies. "More than 70% of the individuals in home sharing do so at no cost to the

state DD office, and only 29.6% of individuals in home sharing are receiving any subsidy from OMRDD. In a majority of instances (58%) home sharers paid rent entirely with entitlements such as SSI, SSDI, and SSA. The developmental disabilities system in New York is becoming more responsive to accepting home sharing situations given that approximately one third of the individuals with developmental disabilities capable of living in home sharing could not afford to do so without additional funding for rent and supports" (DDPC Home Sharing Grant Project Summary, p.15).

New York's Community Services Expansion Plan (CSEP) creates independent housing options, housing-related subsidies, case management and other support services. CSEP broke with the New York Office of Mental Retardation's traditional practice of packaging community service expansion dollars into predefined options. Instead, decision-making was decentralized, consumers and family members were given a more prominent role in local planning to match dollars and service needs, and services were tailored to individual needs in a flexible manner. CSEP has three basic objectives: "more people served, more timely service delivery, and customer satisfaction."

Through CSEP, roughly \$45 million was distributed to district offices which, in turn, collaborated with consumers, families and non-profit providers in using these dollars to leverage Medicaid HCB waiver and other funds to implement person-centered approaches to meeting the needs of people with developmental disabilities. In contrast to the state's former system of expanding community services through the allocation of prefabricated "program packages," CSEP "unbundles" services so that supports can be tailored to each person's needs. State officials estimate that 1,000 more individuals are being supported under CSEP than could have been served using "traditional" program/facility-based community services options (Community Services Reporter, Oct. 1994).

New York has also launched a *loan program* to help the state's *family-care provider network* improve its homes. Roughly 4,400 individuals are served in 2,600 family-care homes across the state. The state of New York's Office of Mental Retardation and Developmental Disabilities is making available three types of loans to current and prospective family care providers: loans of up to \$20,000 to pay for environmental modifications, loans of up to \$5,000 to assist providers in leasing a larger home or to assist new providers in leasing a home that meets certification

standards, and loans of up to \$20,000 to cover the down payment on a home the provider is purchasing or to pay for renovations needed to meet certification requirements.

Ohio's Community Capital Assistance Project purchases housing for persons with developmental disabilities who require supportive living services. The consumer takes an active role in selecting the type and location of the housing, who their roommates will be and how the home is furnished. Existing properties--no new construction is permitted--are acquired with the assistance of local real estate brokers. Each county board of mental retardation that participates in the program (67 out of 88 counties) is responsible for selecting or establishing the non-profit agency that provides the assistance to the consumers. When properties are sold, the proceeds must be reinvested in other acceptable housing.

By 1996, 320 properties had been acquired, providing housing to 810 individuals. Funding for this program has been secured by selling municipal bonds, state Department of Mental Retardation/Disabilities and the Ohio Public Facilities Commission.

A key feature of the Ohio initiative is the *separation of funding for housing and supports*. The Capital Assistance Project provides funding for capital resources, whereas the supports and services component is provided through the state's Supportive Living Program. This separation creatively "permits consumers to change service providers without having to move from their homes."

The state of **Rhode Island** has made \$600,000 available for home ownership for persons with developmental disabilities in a one-year demonstration project called the Mortgage Program for Persons with Developmental Disabilities. New and existing single-family homes and condominiums requiring minimal maintenance are eligible for purchase. Staff from the state Housing Mortgage Finance Corporation are available to help consumers search for property. Staff from the state Department of Mental Health, Mental Retardation and Hospitals will also evaluate properties relative to needed community services, structural condition, and maintenance requirements.

A home-buyer counseling component has been built into the demonstration. The Housing Mortgage Finance Corporation provides initial counseling to make sure participants consider the various housing options available to them and the

responsibilities that home ownership involves. The Corporation provides counseling at both six and twelve months after closing and on an as-needed basis after that. Funding for this project has been made available through a bond issue approved by the state's voters.

In **Illinois**, the Equity Fund for Community Integrated Housing uses federal low-income tax credits to assist local organizations in developing affordable single family homes, condominiums, town homes, and duplexes into homes for three or fewer people with disabilities. To ensure separation of housing and services, properties must be managed by a local development corporation that is not affiliated with the service provider. The program is designed to allow persons with developmental disabilities to buy or otherwise control their housing units. Under this program's guidelines, a limited partnership can be created by a non-profit agency, a corporate investor and the state housing trust fund. The investor will receive the tax credits and the property will be managed by the non-profit agency. The tax credits, which are a central feature of the Equity Fund's design, are allocated to each state by the federal government and can be obtained by private investors in return for developing housing for low-income individuals.

The **Minnesota** Housing Finance Agency (MHFA) operates programs to make homes more accessible for individuals with developmental disabilities. Funds are available through MHFA's Home Improvement Loan Program and Rehabilitation Loan Program. The Great Minnesota Fix-Up Fund and Fix-Up Accessibility Program provide reduced-interest loans for making modifications in the homes of persons with disabilities who are at "risk of institutionalization." Funds may also be used to provide home improvements in one-to-four unit owner-occupied properties. Funds are obtained from the agency's sale of tax-exempt bonds in the national investment market.

Michigan's State Housing Development Authority is currently operating the MI Home (More Independence through Home) Program to assist non-profit agencies in acquiring one-to-four unit residential properties for rental by persons with developmental disabilities. A goal of the project is to make rental housing affordable to persons with modest incomes: Participants pay no more than 30% of their income for rent.

The non-profit sponsor is expected to assume a primary role as owner and landlord, although it may employ professional housing managers to handle day-to-

day operation and leasing. Sponsors must have a feasible long-term support plan for their residents. The program is funded through federal funds from the HOME Program through the Department of Housing and Urban Development (A Guidebook on Consumer Controlled Housing for Minnesotans with Developmental Disabilities, 1996).

New Hampshire's Home of Your Own Demonstration has been implemented through the state's Mental Health and Developmental Services Department and the state Housing Finance Agency (HFA) in collaboration with the University of New Hampshire's Institute on Disability/University Affiliated Program, the state Developmental Disabilities Council, and the state Disability Rights Center. The program purchases single-family homes and condominiums with a maximum purchase price of \$100,000. The HFA set aside \$1.5 million of its standard first-time buyer program especially for persons with disabilities. For down payment and closing costs, the HFA budgeted an additional \$100,000 which has been matched with another \$100,000 from the Mental Health and Developmental Services Department. In addition, financing has been structured through an unconventional use of the consumers' federal Medicaid waiver dollars. "The project demonstrated that service funds and disability-related entitlements, if used imaginatively, can allow people to own homes. The flexible underwriting criteria provided by the primary lender, the HFA, made it possible for individuals living on public benefits without savings or established credit to qualify for loans" (Extending the American Dream, 1994).

Nurtured by a growing consumer movement and supported by the successes of an increasing number of programs, several states are actively promoting the creation of individualized housing development.

V. TESTIMONY OF SPEAKERS AND CONCERNED CITIZENS

Testimony delivered by parents, advocates, professionals, providers and consumers at the Commission hearing in May of 1995 highlighted four major recommendations. This testimony provides compelling evidence of the need to develop a housing and support approach that builds bridges between the housing and disability communities. Building these networks is crucial to ensuring that the needs of people with mental retardation and other disabilities are addressed through regular housing instead of the separate disability system.

The four main recommendations discussed at the hearing and presented in written testimony are:

- Encourage Agency and Systems Change
- Strengthen State Policy Development
- Promote Public/Private Partnerships
- Publicize Promising Practices and Resources

Encourage Agency and Systems Change

Many participants articulated the need to encourage the development of "supportive living approaches" in housing development. Most residential service agencies are used to identifying, assessing, and screening people to determine if they are eligible for services. Making a personal commitment to people means that the agency moves away from "terminating" or "discharging" people from services. Instead, the person, agency, and others may work together to change the person's support services, which might include changing the staff, the housing, or where and with whom the person lives.

"Life sharing means those situations where people make choices to live together without any monetary reward. The agency made a commitment to the people it served and to their families to help them with the creation of home services that were more individualized and more personalized." George Fleischner, Executive Director, Nonatuck Resource Associations

"There is near constant tension between program and home, particularly in situations where staff are almost always present. We use jargon constantly and program mentality creeps in slowly." William Kelly, Executive Director, Beta Community Services

"We at DMR are aware of the need for residential reform. We are expanding our menu of housing options and have been fostering consumer choice through the actions of service coordinators. These individuals have been working to change housing settings to homes throughout the Commonwealth." Ann Lane, Program Development and Operations, DMR

Those attending the hearing agreed that state departments need to learn how to use the experience of individuals to move toward broader systemic changes.

"If people are going to have control over their lives they've got to have control of dollars. Our roles will change. It will dismantle the human service system as we know it. We will become brokers, agents, consultants to individuals if, indeed, we have anything to market to them." Gerry Pilkington, Executive Director, Attleboro Enterprises

"The most exciting part about this is that the consumers and the families have been asking for it. We've done it by listening to the families and the consumers, and working on an individual design or a whole life planning process for the individuals we're involved with. The quality of life is so much dramatically improved by these folks that get into their own individual support settings." Tom Riley, Executive Director, Better Community Living

"What I really wanted to emphasize is really the technologies of how an area can move toward an individualized system. We have created in the area a great deal of involvement of families and consumers. This is done primarily through family empowerment groups and the use of cash assistance. We support 151 individuals in a purchase of service system. And out of those 151 individuals, 98% are living in one- or two-person homes." Bruce Brewer, Area Director, Franklin/Hampshire DMR

Strengthen State Policy Development

There was clear agreement from all participants that states determine how housing is developed for citizens with disabilities. For integrated, individualized housing to become common practice, rather than the exception, the human service delivery system will need to change substantially how it funds and supports residential services.

"DMR regulations force a sense of difference. Neither my wife nor I stay awake all night watching our children sleep, even though my son is not able to evacuate the house in 2 1/2 minutes." William Kelly, Executive Director, Beta Community Services

"As state policy moves toward choice, the issue is moot without concrete living opportunities. Intelligent planning begins with insight at the local level and the willingness to develop real solutions." Maureen Fitzhenry, Community Housing Coalition

"One of the key issues is the segregation of housing policy. The segregation of housing policy means if you look at your public housing programs you have family housing, you have elderly housing and for people with disabilities, you have special needs housing. What we really want to do is to provide for regular, normal integrated housing where everybody lives." Tom Anzer, Special Assistant for Policy and Public Education, Department of Mental Health

Participants echoed the need for the state DMR to separate housing and support services and to explore new ways to work with state housing departments. This separation aspect will involve unbundling the financing between housing and services, changing legislation, regulations, and policies that may prohibit people from living in their own homes.

"Public policy must be created around the housing issue and how both resources and dollars are allocated. This policy must pay close attention to keeping the focus on the individual, not large service systems; to collaborative efforts, not just block grants, and insure that such policy mandates consumer control and choice. It is not choice if the agency is awarded monies for accessible housing. Award it to the individuals and let them choose where they live, design what they want, and contract with whom they choose." Catherine White, Executive Director, ARC Northern Bristol County

"Policies, practices, and expectations regarding home and home life will respect and support a person's chosen lifestyle, affiliations and activities. These visions and principles are not a mandate or a road map for how to proceed for DMR, but they are a direction." Bertha Blaney-Young, Program Development, DMR Central Office

Department of Mental Retardation Vision of Home and Home Life

- √ The nature of an individual's home life will be defined primarily by the individual who resides there. Resources for home ownership and rental assistance will be adequate and available to individuals directly.
- √ Housing and paid personal assistance, while interrelated, will be separately controlled.
- √ Supports will foster as much choice and control as possible and be sufficiently flexible to accommodate people's changing preferences.
- √ Policies, practices and expectations regarding home and home life will respect and support a person's chosen lifestyle, affiliations, and activities.
- √ Each person's unique capacities, gifts, and talents will be celebrated in the home and community and will be the foundation for how supports are designed and implemented.
- √ Individuals will be assisted to assume as much responsibility as possible for their own lives.
- √ Home will create the conditions for developing, sustaining, and strengthening freely given relationships.
- √ People with mental retardation will be supported to live in and be part of their communities. Non-disabled citizens of the community will be supported to be in relationships with persons who are mentally retarded.
- √ People who are in a person's life on a regular or daily basis-family, friends and paid assistants will be recognized and valued.
- √ Every person with mental retardation will have a place that is a real home.

(September 1996)

"Traditionally, funding has been given to providers to rent property or have providers purchase homes through different grants or agencies rather than having the option for people to purchase their own homes....Why can't state dollars be given to individuals that we've been serving (and we've been serving people for 20 years) who have been paying rent so they could now own their own home? State policy makers need to review their old policies to incorporate innovative opportunities for housing development." Nancy Silver-Hargreaves, Executive Director, Waltham Committee

Baybank Program

Baybank has committed \$500,000 in mortgage loans,
Relaxed requirements for debt-to-income ratio,
Relaxed requirements for origin of the down payment,
Relaxed credit history requirements and flexible income source parameters.

In May, 1996, 4 individuals from Fernald bought their first home in Belmont.

In June, 1996, 2 consumers from Waltham Committee Inc. purchased a home in Watertown.

In August, 1996, a mortgage was finalized on a home in Westfield for one person.

Promote Public/Private Partnerships

Participants agreed that alliances among consumers, human service professionals, parents, disability advocates, and existing affordable housing coalitions need to be developed.

"I'm actually excited about the potential partnership with parents, professionals, as well as DMR can achieve if they work together." John Nadworny, Parent, Families Organizing for Change

"I think where more work needs to be done is to create options and alternatives for families to be able to make significant commitments, but know that the state is there to help them with that." Jeffrey Sacks, Attorney, Brown, Rudnick, Freed, and Gesmer

"We are creating partnerships and interagency networking between state agencies, non-profits, housing associations and communities." Ann Lane, Program Development and Operations, DMR

"We need the public, the private sector, the business sector, the FDIC...all of these agencies and groups need to work toward putting homes together for individuals." Carl Bruhn, Family Advocate, West Boylston Housing Authority

There were several suggestions about ways current human service agencies could become more involved in collaborative projects with the housing community.

"One innovative response to our RFP had a housing development entity and a service provider file a joint application. This provided the best flexibility for everyone." Tom Anzer, Special Assistant for Policy and Public Education, Department of Mental Health

"I just want to thank you so much for giving me this opportunity and allowing this to happen...the lawyers, the bankers, the brokers, everyone. This is what needs to happen with people..Now we have our own condo, and we're so happy about this." Renee Miranda, Homeowner

"The points I wanted to make tonight primarily are a plea for more interaction and more information between the DMR community and the housing development community. We are a source of expertise. We would like nothing better than to partner up with clients, with their families, with service providers, with DMR and other folks and bring our knowledge to the table to help with the legal, engineering, construction, and most of all the financing, which is really a process of making stew." Andy Howarth, Associate Executive Director, Rural Housing Improvement

Publicize Promising Practices and Resources

Many participants "applauded" the efforts of the Commonwealth to establish a variety of innovative affordable housing and support programs. A spectrum of housing options is crucial to the successful shift towards independent living; it must be accompanied by an equally diverse selection of support options.

Housing Finance Programs

Community Economic Development Assistance Corporation (CEDAC)

- √ provides technical assistance to non-profit organizations to help plan housing and economic development;
- √ assisted 191 non-profits build 7,246 units of housing in 71 communities;
- √ working on developing an additional 8,428 units.

CEDAC is the underwriter for the \$30 million Housing Innovations Fund and the \$50 million Facilities Consolidation Fund administered by the Executive Office of Communities and Development (EOCD). These funds are targeted for persons with developmental disabilities and mental illness to facilitate the development of community-based housing. *"The goal of the administration through this program is to help finance a comprehensive network of community-based alternatives providing more normal and cost effective residential care."* Charleen Regan, Senior Project Manager, CEDAC

"We have an eagerness and a willingness to do this. Current discussions include working with parents who have children aging in place. We are exploring the possibility of pooling two, three and four families' resources together in order to provide a trust to buy real estate." Bill McDevitt, Section Chief, Affordable Housing FDIC

**Federal Deposit Insurance Corporation
(Affordable Housing Program)**

- √ provides below-market interest rate funds for low and moderate income homeownership, rehabilitation and rental housing developments;
- √ designated four to five hundred housing units in Massachusetts;
- √ FDIC is a valuable tool and resource able to work with a variety of organizations and disciplines;
- √ initiated a pilot with CEDAC to sell its multi-family apartment buildings to non-profit organizations.

"The nine members of the Massachusetts Non-Profit Housing Association, along with the statewide network of Community Development Corporations and numerous city and town community development departments, form a resource base which can partner up with service providers to develop a variety of state, federal, and private financing sources. Together we can make a whole field of innovative flowers bloom in the provision of housing for Massachusetts' retarded citizens and their families." Andrew E. Howarth, Associate Executive Director, Rural Housing Improvement, Inc.

Executive Office of Communities and Development (EOCD)

EOCD is the state's lead agency for housing and community development programs and policy. It oversees the state-funded public housing, administers rental assistance programs, provides funds for municipal assistance, and funds a variety of programs to stimulate the development of affordable housing. EOCD contracts with nine private, non-profit housing agencies to administer its Section 8 program on a statewide basis. These non-profit housing agencies also provide technical assistance and training on housing development in communities.

Many families spoke about a relatively new area in financing community housing development--housing trust funds. Housing trust funds are dedicated sources of revenue--interest on real estate escrow accounts, for example--that are committed to providing low and moderate income housing.

Wrentham Developmental Center Irrevocable Trust Fund

Trust fund monies purchased a two-bedroom condominium;
Planning, development and implementation took two and a half years;
Extensive collaboration between DMR, trustee, consumer and service provider;
Consumer acquired home of his own.

Mary Akoury, Community Services, WSS

There are many government, quasi-public, private non-profit and private for-profit entities involved in developing or financing affordable housing, or providing key support services. The legislature created the **Massachusetts Housing Finance Agency (MHFA)** in 1966 to help finance affordable housing programs. MHFA sells both taxable and tax-exempt bonds to private investors, and also finances loans for single family and multi-family housing. To date, MHFA bonds have financed over 69,000 rental units in mixed-income projects and over 28,000 home mortgages and home improvement loans. *"We and DMR have a set aside in mixed income housing developments of 3% of all the low-income units. That is based solely on a commitment that we will be there when any consumer that we place there needs us for as long as they live there. This program has worked and its been a successful program."* Tom Anzer, Special Assistant for Policy and Public Education, Massachusetts Department of Mental Health

Housing Options

Testimony from many participants echoed the need for extensive discussions on the use of alternative housing options for supporting adults with disabilities. Options discussed included the development of cooperatives and housing associations, housing subsidies, and general resources and organizations that deal with housing issues within the context of the larger community.

*"We are a small grassroots group called the **Community Housing Coalition**. The coalition is a subcommittee of Foxboro's Board of Selectmen and was initiated by a citizen request. The origin of the coalition coincides with the redevelopment plan for approximately 175 remaining acres of prime, multi-million dollar parcel known as Foxboro State Hospital. It is the wish of the coalition that these homes not be vendor-operated but instead controlled either by lease, ownership or some form of limited equity, cooperative arrangement. The coalition is attempting a modest effort to explore the concept of rural community collaboration to develop a range of adult living options."* Maureen Fitzhenry, Community Housing Coalition

"This model seems to be the right thing for our son because we expect he will need support from other people all his life, and this model creates a supportive community in which a natural blending of professional staff (in his own unit), peers

and friends with special needs, neighbors, and other community members will occur over time" Susan Sternfeld, Parent

What is Co-housing?

Co-housing is a cooperative community model that combines residential privacy with the benefits of collective life. Individual household units are located near a shared common house for community meals, child care, laundry, recreation, guest quarters, and other facilities. The development can be accomplished by building on open land or by remodeling a large urban building. In the course of planning and developing a site, future residents also build a community spirit and group process that support the life of the community.

The **Pomeroy Lane Housing Cooperative**, designed by Amherst architect Peter Kitchell, consists of 25 apartments and town houses for 71 residents of varied races and income levels. It also includes four units set aside for people with mental retardation. The Pomeroy Lane Housing Cooperative was developed by a group called ABODES (Amherst Based Organization to Develop Equitable Shelter), which was founded in 1989, in order to find "housing for the long-term, financially secure housing for developmentally disabled adults." Funding for this project was secured through a Community Development Block Grant through the town of Amherst, and additional assistance was provided by the Community Builders of Springfield. Residents purchase shares in the housing cooperative and subsequently have "ownership" in the project. Each share is \$1,200 regardless of unit category, and residents participated in a training program conducted by the non-profit

organization, ARCH (Association for Resident Controlled Housing). The co-operative is run by a board of directors with support from a housing management company. One resident told a neighbor "I keep pinching myself to make sure it is true."

Specialized Housing, Inc. has been providing supported residential opportunities for adults with developmental disabilities for ten years. There are 68 adults living in condominium lodging house situations and supervised apartments in Brookline and Cambridge, Massachusetts, and Providence, Rhode Island. *"We work with people who are not priorities for receiving housing services from public agencies but need support to be living independently."* Margot Wizansky, Specialized Housing Inc. The family or a trust owns the unit in most cases, and the adult occupying the unit is supported in living as independently as possible. Support staff is on the premises to assist with whatever the individual needs.

*"I'd like to share with you an existing **Community Housing for Adult Independence Plan (CHAI)** which is sponsored by the Jewish Family Services in Brighton, Massachusetts. CHAI is a service model that addresses the support needs of 15 people living in individualized apartment settings.*

Staff are available to the consumers, who have learning disabilities, developmental disabilities, or mental health support needs. Each consumer has a part-time or a full-time job, or is involved in community volunteer work. The consumers live in their own apartments, receiving staff service of one to four hours a week. On-site staff and 24-hour on-call support are provided." Juliette Lemelin, CHAI

"I left my parent's home in 1983 to go on my own. I was in living situations with roommates I did not know. Now I live in CHAI. Now, I can live independently and have support in carrying out activities as well. I'm happier now and continue learning about myself."

Stuart Feldman, Self-Advocate

Support Options

Many participants acknowledged that a major new role of the residential agency is to support people to fulfill their own hopes and wishes, recognize and develop skills and interests, attain personal wellness and safety, and participate fully in community life.

"While there are several person-centered planning approaches, the one we use is Personal Futures Planning developed by Beth Mount. We help a person explore their preferences, develop a profile of themselves and then create a vision for their future. They are then assisted to invite friends, family and the professional resource people in their life to form a circle of support to help them achieve this vision. This approach leads people to consider many housing options with a focus on where the person wants to live and with whom." Sarah Page, Executive Director, Family Empowerment Program

"We have explored alternative models to DMR staffing of supports, applicable to people low on the priority scale for DMR eligibility. One appealing possibility is to use Personal Care Assistants. We have learned to work with consultants and agencies to expand resources. Our purpose is to support each other and assist our family members in exploration of all aspects of supported independent living." Mary and Gordon Wyse, Parents Allied for Quality Independent Living (PAQUIL)

VI. RECOMMENDATIONS

"If you can only do one thing, let it be to unite us in policy then practice."

--Catherine White, Executive Director, ARC Northern Bristol County

How persons with mental retardation and their families become aware of and access housing is a complicated process. If the Commonwealth is to be true to its mission of meeting individual needs, we must encourage the development of housing options and supports that are simple and responsive to the consumer.

Housing and the need for housing are not new issues. Communities have developed mechanisms that are available to the non-disabled individual and family to help them realize their housing needs. Historically, the Commonwealth has ignored the availability of generic funding streams and housing opportunities in favor of state-funded, provider-operated and renovated homes to serve groups of persons with mental retardation. For integrated, individualized housing to become practice, rather than the exception, the Commonwealth will need to change substantially how they fund and support residential services.

There is no single strategy. All options for housing must be investigated, and where appropriate, utilized to meet the overwhelming need. This report has reviewed some critical dimensions of state systems that have moved toward a housing and support approach--new ways of thinking about planning, financing, capital acquisition and program development. The Commonwealth needs to review the dimensions of these and other state systems in order to encourage the development of systemic state policy and program change.

The following recommendations are offered to further the development and support of individualized housing and support for persons with mental retardation:

- *The Commonwealth needs to adopt clear policies on housing and support for persons with mental retardation and other developmental disabilities and provide leadership in developing implementation strategies.*

Housing policies need to clearly articulate the principles and goals of "consumer controlled housing." This approach is based on the principle that adults have a right to live in a home in the community with whatever supports are necessary. The basic service characteristics of this approach include: (1) the separation of housing and support services; (2) the promotion of home ownership and integrated housing; (3) individualized and flexible services and supports; (4) individual assessment, planning and funding; and (5) consumer-directed housing and service development.

In 1994, former Health and Human Services Secretary Baker defined a role for agencies as they design their residential development processes, "consumer choice is the foremost responsibility of EOHHS agencies in the residential development process" (Initiative to Promote the Facilitation and Coordination of Residential Development for Consumers Served by EOHHS Agencies, 1994).

In September of 1996, the Department of Mental Retardation issued a final report which describes a new direction for the agency in order to "begin to bridge the gap between the current residential system of supports to people and the vision of home and homelife" (DMR Vision and Recommendations on Supporting People's Homes and Lives, 1996).

The Governor's Commission on Mental Retardation would like to applaud and commend DMR for this effort to substantially change how they fund and support residential services. However, this effort requires an inter-agency, cross-disability/community approach. Housing is first and foremost a community issue. Communities need to understand the importance of integrated, individualized housing for persons with disabilities. Effective inter-agency collaboration and coordination with community leaders is necessary if persons with disabilities are to be adequately supported in personalized housing options. Information sharing and training should be directed to families, realtors, bankers, housing developers, legislators and other community leaders on the benefits of individualized supported housing.

The Governor's Commission on Mental Retardation recommends the establishment of "working groups" within the Executive Office of Health and Human Services to develop a strong partnership of people with disabilities and professionals in both human services and the housing industry to begin sharing

needed expertise. DMR needs to be an active participant at this table, however, the charge needs to come from the Executive Office of Health and Human Services in order to establish a broader housing coalition. Testimony presented at this public hearing as well as research studies conducted from other states provided ample evidence that building alliances between the disability field and other community organizations offers the potential for greater creativity in generating solutions that will enhance community membership.

- *The Commonwealth should develop a clearinghouse to provide up-to-date information on all available funding programs, applications, technical assistance resources and housing and service providers in each region. Specific information targeting the variety and flexibility of support options should be included in this database.*

Despite an impressive array of programs and services, few individuals or agencies can quickly and reliably learn about all possible resources. Programs often get started as a result of crises and tend to target particular sub-groups of the population. The clearinghouse would be especially helpful for private and non-profit developers and families interested in securing resources for small home adaptation and homeownership projects.

The Governor's Commission on Mental Retardation commends the Massachusetts Rehabilitation Commission and the Citizen's Housing and Planning Association for establishing Mass Access, the Accessible Housing Registry. Mass Access will provide current vacancy information to disability agencies across the state regarding accessible housing units, however provides no information about the variety of flexible support options available to consumers in the Commonwealth. The state needs to expand this directory to include the organizational, personnel, and financial resources currently available within the state to assist in the financing and development of personalized housing options. This clearinghouse should be accessible to individuals with disabilities, state agencies, private developers and providers. People with disabilities, agencies, and community leaders need to be informed about the possibilities of integrated, individualized housing and support options.

- *The Commonwealth must provide additional training in the development of individualized housing and support options for individuals with disabilities.*

The availability of a range of options in both housing and services is crucial to the successful shift towards independent living. This respects the freedom of choice of people with mental retardation and allows a person's living situation to change as his or her needs evolve. No single residential model provides the solution for all.

Many providers have limited experience in supporting adults in more individualized and flexible ways. Disability agencies must play a role in assisting providers to obtain this expertise. These roles can include encouraging and supporting creativity on the part of providers, addressing systems barriers as they are identified through the program development process and ensuring the adequacy of funding and resources. State policy and procedures must be responsive to the needs expressed by providers and other community developers in designing supportive housing options.

Successes in the development and support of individualized housing need to be more widely publicized and shared. To benefit from others' experiences, there needs to be ongoing documentation and evaluation of what happens when smaller, more personalized housing and support options are put in place. This training should be directed to a variety of audiences including: people with disabilities, developers, residential providers, and leaders in housing development in state government.

States have a highly influential role in determining how housing is developed and provided for citizens with mental retardation and other disabilities. To ensure the development of integrated, individualized housing, the Commonwealth needs to review and enhance the existing system.

The recommendations and ideas presented in this report are provided to initiate discussion to promote, develop and secure quality housing and support opportunities for individuals with mental retardation and other disabilities.

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